

## Welcome to Our Latest Edition

*Our goal is to provide a medium for VA MS professionals to share expertise and improve care for MS patients. We welcome your thoughts, comments, and participation.*

*Please pass this issue along. If you know someone who wishes to be included on the electronic distribution list, forward the e-mail address to the editor.*

---

## A Letter from the VA-SIG Chair

Dear Colleagues,

I hope that this time of year finds you all well. I am keeping those of you who experienced the devastating effects of the horrendous hurricane season in my thoughts.

Our VA-SIG is plodding along and working hard to develop programs and update the VA-SIG membership. We are looking at ways to improve the VA-SIG meetings at the Consortium of Multiple Sclerosis Centers (CMSC) conference and try to offer more time for informal get-togethers for exchange of ideas.

As chair, I have the opportunity to meet many brilliant VA people who are doing ground-breaking research in the MS field. It is so rewarding to sit and listen to the “best of the best” discuss their research. At times we all get so bogged down with the daily clinical issues that it is hard to think “outside the box.” It is refreshing to listen to researchers update us on the latest breakthroughs. Their dedication and hard work will lead us to a cure for MS.

Some VA-SIG steering committee members had the opportunity to attend the “John Whitaker Symposium,” sponsored by the MS CoE–West. The lecture, which covered developments in the field of genetics and outlined possible genetic similarities that have been found between Parkinson’s Disease and MS, was aptly described by one attendee as “mind boggling.” I had the opportunity to attend the CoE–East coordinators meeting and listen to top East Coast researchers discuss the progress of their complex MS research. It really is an awesome experience to realize the brilliance of the minds of our VA researchers.

With research in the forefront in our VA system, it is with pride that our VA-SIG acknowledges Dr. Albert Lo, who recently received the Presidential Early Career Award for Scientists and Engineers in recognition of his achievements and potential in the field of neurology research (see story page 7). We are very proud of Dr. Lo and are honored to have him chair our research committee.

In closing, I encourage everyone to participate in research programs at your respective VAs.

Sincerely,

Rachel L. Palmieri  
VA-SIG Chair

## Letter from the Editor

With sadness but many, many thanks for all the time, effort, and talent she contributed to making this newsletter so successful, we say goodbye to Deborah Livingstone. Debbie, *VA Signature's* founding editor, resigned the position during the summer. However, she continues to follow the activities of the VA-SIG and would be happy to hear from you at [deborah.livingstone@med.va.gov](mailto:deborah.livingstone@med.va.gov).

In this issue you will find stories focusing on:

- the MS Centers of Excellence,
- news from VA centers around the United States,
- membership, and
- important dates.

We will continue to present articles that focus on MS when possible.

We call your attention to the section on activities in MS centers around the country. This section allows us to highlight the creative endeavors in which you are involved that affect the lives of our veterans with MS. We hope this section will encourage others who are doing interesting things to share them with us. Our goal is for this section to lead to more and more supportive and educational activities for veterans with MS, caregivers, and clinicians, affirming the goals we had in creating the VA-SIG of MS Providers.

I close with a plea: This is your newsletter. It will be a better communication tool with your help. Send us:

- ideas to improve *VA Signature* and the VA-SIG;
- stories on what you are doing of interest;
- questions about anything (we may establish a question and answer section in *VA Signature* but will also answer you directly or forward your query to someone who can answer); and
- articles on MS and/or names of people whose work should be shared with this audience.

And a second, very important request: Please check out the membership section. We are working hard to make sure all VA medical centers with active MS programs are members of the CMSC. Some of you will find your medical center is not a member and should be. Others may work at the few Centers that are members but not active, at which we cannot identify the people doing the MS work.

I look forward to hearing from you,

Elizabeth Auld, PA-C  
[elizabeth.auld@med.va.gov](mailto:elizabeth.auld@med.va.gov)

## VA-SIG MEETING ANNOUNCEMENT

The next full business meeting of the VA-SIG will take place in Orlando, during the annual Consortium of Multiple Sclerosis Centers 2005 meeting, to be held at Walt Disney World Swan and Dolphin Hotel June 1–5, 2005. The title of the meeting is Navigating the World of Multiple Sclerosis. VA members are encouraged to submit abstracts for presentations and posters. The deadline for submission is January 14, 2005. More information is available from the CMSC Web site: [www.ms-care.org](http://www.ms-care.org).

In 2005 the VA-SIG Steering Committee is planning to expand opportunities for VA clinicians to meet and discuss issues relevant to MS in the VA System. There will be opportunities to join committees of the VA-SIG and help in our work, and the VA MS Centers of Excellence will present a symposium.

A limited amount of funding is available to support attendance of VA members from the Paralyzed Veterans of America and United Spinal Association. VA members are strongly encouraged to apply early to their home facilities for funding and to explore other options to support their attendance at this important and exciting meeting. We hope to see many more of you at this next meeting.

## Neurology Day Program

The Neurology Day Program at the Boston VA Health Care System is a multidisciplinary program of socialization, group support, and health education for patients with chronic neurological disease. Although most of the members have multiple sclerosis, it is not a requirement for admission. Over the years, a few patients with other illnesses, such as muscular dystrophy and chronic pain, have greatly benefited from this program.

In 1978, a multidisciplinary group of clinic staff designed the pilot program for a group of 10 patients with a chronic neurological illness, disabling enough to interfere with occupation, activity, and/or social functioning and for whom transportation could be arranged every two weeks. These patients also had to be able to withstand a full morning of activity and be willing to engage in program activities on a regular basis. The response of the veterans to this program was overwhelmingly favorable and enthusiastic. A monthly support group for caregivers was added, and this, too, was well received and attended.

Initially the program included time for socialization, health education, group support, occupational therapy, and group exercise. This schedule soon proved to be too strenuous for the group. The program was

redesigned, and occupational therapy and group exercise were eliminated. Later, because of staff constraints and transportation issues, the meeting frequency was reduced to monthly.

### Neurology Day Program Schedule

8:45–9: Patients arrive in clinic. Transportation provided by VA, The Ride, or private car/van as needed.

9–10: Coffee/Socialization/Informal group education. Nurse, neurologist, and patient volunteer available to answer questions, manage health-care issues, and assist as needed.

10–11: Patient Education Program. Guest speakers from various health-care disciplines as requested by group.

11–12: Support Group. Group leaders over the years have included social workers, nurses, and psychologists.

### Group Description

At present, our 18 group members are male, between the ages of 48 and 72. The majority of patients require wheelchairs, and three of those need motorized wheelchairs.

Fourteen of our patients are married, and the others are single, never married, or divorced. Most of our patients live at home with their families or at home alone with support from VA and community services. One patient lives in a nursing home. All but three patients are service connected. The nonservice-connect-

ed veterans are not charged copayments because of their low incomes.

Initially, team members had some concerns about grouping service-connected and nonservice-connected veterans together. There were also concerns about including patients living in a nursing home, ambulatory patients, and those requiring motorized wheelchairs in the same group. However, these issues did not present a problem. In fact, the group members were very helpful and supportive of one another.

The more physically disabled patients welcomed the opportunity to share coping strategies with the less disabled. Ambulatory patients learned that even if the disease progressed, group members and VA would be there to help them.

The Neurology Day Program has had a few female veterans with MS. However, this year there were enough women with MS to begin a separate support group. There has also been more interest this year in starting a new group for caregivers, to begin this month. Caregivers sometimes prefer to use the group meeting time for a morning of respite.

### Program Evaluation

Discussions with patients/caregivers and written evaluations clearly indicate that, as a result of the Neurology Day Program, patients have a better understanding of their illness, treatment options, and coping strategies and are more aware of resources in VA and the community. In addition, Neurology Day Program staff now better understanding the medical, psychological, and social impact of a chronic, often progressive, illness on the patient and family.

Janet Mudarri, RN, MS, CRRN

### Does your Center have programs for MS Veterans? Educational? Support? Other?

Please consider sharing with us  
what you are doing and how you are doing it.

Do you have questions about programs described here?  
You can contact the authors via Outlook Mail,  
or contact the *VA Signature* editor.

## MEMBERSHIP UPDATE

For nearly 10 years, through the generous support of the former Eastern Paralyzed Veterans Association (now United Spinal Association), VA Medical Center MS Programs have been eligible for membership in the CMSC. This membership led to the formation of the VA Special Interest Group and, by extension, to this newsletter.

One goal of the VA-SIG is to encourage VA participation in activities of the CMSC. This means that all VA Centers with active MS programs should consider membership and that those centers actively participate by keeping in touch with the VA-SIG and the CMSC. At best, we hope that clinicians from all VA center MS programs attend CMSC meetings and become involved in the VA-SIG.

*A list of member centers follows. As you read through the list, please note centers in **bold**, indicating I have not been able to reach anyone there to update the membership. If you work at one of those centers, please contact me. If your center is not on the list, it is not currently a member.*

Some people may think their MS program is not big enough to qualify as a “center”; however, the most important requirement for VA membership is an interdisciplinary MS program. All VA medical centers offer many of the treatment modalities that make up interdisciplinary care for MS patients (urology, rehabilitation, prosthetics, psychology). All that is required is a director (neurologist, physiatrist, spinal cord physician) who makes referrals to these other areas. If you or your center is

interested in becoming a member, you can contact me, and I can send you the application electronically. Or contact CMSC at [www.mscares.org](http://www.mscares.org) and request an application.

There are no onerous requirements for members—membership dues are paid by PVA and USA. We hope to improve communication between the members, VA-SIG, VA MS Centers of Excellence, and the CMSC. The first step is to ensure that most MS programs in the VA system are members. This is an exciting time in the history of MS care in VA, and we encourage all of you—members and members to be—to work with us to make the most of this opportunity.

Albuquerque VAMC  
**Alexandria VAMC**  
**Atlanta VAMC**  
 Augusta VAMC  
 Baltimore VAMC  
 Birmingham VAMC  
 Boston VAMC  
 Brooklyn VAMC  
 Buffalo VAMC  
 Charleston VAMC  
 Chicago VAMC  
**Chillicothe VAMC**  
 Cleveland VAMC  
 Columbia VAMC  
**Dallas VAMC**  
 Dayton VAMC  
 Denver VAMC  
 Durham VAMC  
**East Orange VAMC**  
 Fresno VAMC  
 Hines VAMC  
 Indianapolis VAMC  
 Jackson VAMC  
 Lebanon VAMC  
**Little Rock VAMC**  
 Manchester VAMC  
 Miami VAMC

Minneapolis VAMC  
 New Orleans VAMC  
 New York VAMC  
**North Chicago VAMC**  
 Northport VAMC  
**Palo Alto VAMC**  
 Philadelphia VAMC  
 Phoenix VAMC  
 Pittsburgh VAMC  
 Portland VAMC  
**Prescott VAMC**  
 Salem VAMC  
 Salt Lake City VAMC  
 San Antonio VAMC  
 San Juan VAMC  
 Seattle VAMC  
 Tampa VAMC  
 Togus VAMC  
**Topeka VAMC**  
**Tuscaloosa VAMC**  
**Tuskegee VAMC**  
 Washington DC VAMC  
 West Haven VAMC  
 West Los Angeles VAMC  
 Wilmington VAMC

### VA-SIG STEERING COMMITTEE MEMBERS:

**Rachel Palmieri, RN**  
[rachel.palmieri@med.va.gov](mailto:rachel.palmieri@med.va.gov)  
 Chair

**Christine Martin, PhD**  
[christine.martin@med.va.gov](mailto:christine.martin@med.va.gov)  
 Vice Chair

**Peggy Coffey, MD**  
[peggy.coffey@med.va.gov](mailto:peggy.coffey@med.va.gov)  
 Chair, Clinical Care Committee

**Elizabeth Auld, PA-C**  
[elizabeth.auld@med.va.gov](mailto:elizabeth.auld@med.va.gov)  
 Chair, Membership Committee

**Albert Lo, MD**  
[albert.lo@med.va.gov](mailto:albert.lo@med.va.gov)  
 Chair, Research Committee

**Lynne Walker, RN, CRRN**  
[lynne.walker@med.va.gov](mailto:lynne.walker@med.va.gov)  
 Chair, Education Committee



## NEWS FROM MS CENTERS OF EXCELLENCE

CoE–East, Baltimore:

The MS Center of Excellence–East (MS COE–East) held its VISN 1–11 MS Clinic Directors and Coordinators Meeting in Baltimore September 19–21. A key focus for the meeting was the kickoff for two MS CoE East studies: a longitudinal study of Veterans Health Administration (VHA) users with MS and a preliminary study of the effectiveness of academic detailing on the use of disease modifying treatments. The meeting started with a Sunday evening welcome reception, which provided an informative overview from each regional MS clinic director regarding highlights of their centers, models of care, research interests, and patient population.

The first of two full days of educational activities started with a keynote address by John Kurtzke, MD, who presented a broad view of the epidemiology of MS, including a discussion of his many key contributions to the field. Mitchell Wallin, MD, MPH, MS director at the Washington, DC, VAMC, then presented an overview of the contributions of past longitudinal studies to the understanding of MS. A discussion of a proposal for a multicentered longitudinal study of veterans with MS, designed to evaluate different predictors of outcomes in MS patients, followed. This study will also provide valuable information on the characteristics of the veteran MS population, which is needed by planners in VA Central Office. Joseph Frank, MD, from the National Institutes of Health, presented sever-

al aspects of the study, including details of the protocol for MRI acquisition and analysis.

Day two of the meeting included the kickoff for a second study designed to evaluate the value of an academic detailing intervention for residents. The study will incorporate the use of video conferencing to present uniform, unbiased information on the indications and guidelines for prescribing disease modifying therapies to providers in VISNs 1–11. The effect on resident knowledge and self-efficacy with regards to prescribing DMTs will be determined. The academic detailing study began in November.

The second day of the meeting also included additional talks relating to the longitudinal study and other potential collaborative research areas. Michael Levin, MD (Memphis), spoke on the application of genomics and proteomics to the study of MS. Jeffrey Harrow, MD (Tampa), discussed a chronic disease model of care and its application to the MS population. Albert Lo, MD (West Haven), gave an update on current NARCOMS Registry data, trends, and the potential for collaborative studies with the longitudinal study and VA registry of VHA users with MS. The meeting ended with an open discus-

## SHORT ON TIME? WANT TO KEEP ABREAST OF MS RESEARCH?

*MS Scan*, an interdisciplinary publication that reviews current MS research, is available to any one interested in receiving it. The editor, Dr. Cira Fraser, is a member of CMSC and the International Organization of MS Nurses.

To register for this free publication, contact BioScience at (212) 704-4539 or [msscan@bioscicom.net](mailto:msscan@bioscicom.net).

sion of areas of mutual interest that could form the basis for future multicenter research initiatives.

Christine Martin, PhD  
Associate Director for Education

## PUBLISHING OPPORTUNITY

The *International Journal of MS Care* is the official publication of the CMSC, Rehabilitation in Multiple Sclerosis, and the International Organization of MS Nurses. It welcomes submission of articles on topics of interest to MS care providers, including physicians, nurses, rehabilitation specialists, psychologists, and social workers. Submission information and inquiries should be directed to the following address:

IJMSC, c/o Clinicians Group  
1515 Broad Street  
Bloomfield, NJ 07003  
Phone: (973) 954-9300  
Fax: (973) 954-9306

If you have ideas for articles, contact the journal editors. Writers and editors at the journal can guide you through the process.

The journal can be found through the CMSC Web site ([www.ms-care.org](http://www.ms-care.org)) or directly at

www.ms-care.com. Volume 6, Issue 2 contains an editorial by John Kurtzke, MD, "Epidemiological Theories Seek True Etiological Nature of MS," and 2 peer-reviewed articles, "How Does Fatigue Affect Communication?" and "The Incidence of Pressure Ulcers in People with Multiple Sclerosis."

## HANDY REFERENCE

The CMSC has developed an online newsletter that provides links and highlights to information the its Web site. Information includes highlights from the annual meeting; a calendar of events; reviews of books and materials; articles by MS Experts; *MS Exchange*, the official newsletter of the International Organization of Multiple Sclerosis Nurses and the CMSC; presentations on MS topics that can be downloaded, *VA Signature*; a link to the *International Journal of MS Care*; and information on next year's meeting in Orlando, Florida. To register to receive the newsletter, go to [www.ms-care.org](http://www.ms-care.org).

## NEWS FROM AROUND THE COUNTRY

### Iowa City

The VA medical center in Iowa City, Iowa, recently held the 2nd Annual Primary Care/Specialty Clinic Education Conference for the center's medical professional and support staff. Topics included conflict resolution, stress management, post traumatic stress disorder, women's health, diabetes, approach to renal failure, and an overview of multiple sclerosis. The goals for the MS update were two-fold: first, to improve the knowledge base on MS and, second, to promote awareness of the MS Centers of Excellence.

The conference was privileged to have Lynne Walker, RN, from the MS Centers of Excellence—West Education and Clinical Care team, present the multiple sclerosis lecture. She has more than 30 years of nursing experience with MS patients, currently at the Puget Sound Health Care System Hospital.

Donna Healy, RN

### Pittsburgh

The VA MS Centers of Excellence have been a great source of information for the Pittsburgh VA Neurology Clinic. It was not until we received a call from Christine Martin, associate director of Education at the MSCoE—East, asking about programs available for MS patients, that we began to consider that there might be a better way to serve our MS veteran population.

That call was the seed that we needed to start the growth of our new program. We wanted the MS support group to be available for all veterans. The Pittsburgh VA Neurology Clinic is the hub or only neurology clinic for our spoke hospitals such as Erie, Altoona, and Clarksburg along with the outlying satellite primary care clinics. We wanted to ensure that the program could provide certain services. Along with supplying basic support or a forum that patients could discuss experiences, we wanted to provide a more holistic program. We wanted the veterans to be able to network with other veterans with MS, provide education, encourage socialization, offer an exercise program, and make available a wide range of services to the veteran.

The support group almost did not get a chance to sprout due to the lack of available resources. Instead of saying it could not be done, we proceeded to think of it as a challenge. An idea was germinated to coordinate the support group through the VA Adult Day Care Program. They already had the infrastructure of staff and available space in place. The Day Care program also already provided veterans with a place to socialize and other activities such as exercise, arts, crafts, and luncheons. Keith

### For this Newsletter:

***What would you like to see here? Please submit:***

- Forum topics
- Clinical questions
- Research topics
- Ongoing MS projects
- QI issues
- Outcome measurements
- Team initiatives
- Announcements

***Contact the editor at  
elizabeth.auld@med.va.gov.***



*Does your facility have similar educational events?*

*Would you like to have representatives of the MS Centers of Excellence present MS updates at those events?*

*Or would you like the help of the Centers of Excellence in educational efforts?*

*They encourage your requests and will help as much as possible. Their contact information is available at [www.va.gov/ms](http://www.va.gov/ms).*



Zanotti, program leader for the Adult Day Care Program, also saw this as a way to cultivate a new group of veterans for his program. Those who live a distance a way can come one day a month for the MS support group, while local veterans may come on a daily basis if they wish.

Our hope is that with the continued nurturing of the program we will branch out and be able to assist more veterans.

Maryann Hibbs, RN  
Pittsburgh VA HCS

## EDUCATIONAL OPPORTUNITY

The Multiple Sclerosis Comprehensive Treatment Training Program offers a two-and-a-half day preceptorship at the University of Texas Southwestern Medical Center at Dallas. Fourteen sessions will be offered in 2005; each is limited to 10 participants. All costs are covered. Neurologists, neurology residents, and qualified allied health-care professionals (e.g., physician assistants, nurse practitioners, or nurses with advanced clinical training) are encouraged to apply. For more information call (214) 648-9559 or write [mstraining@utsouthwestern.edu](mailto:mstraining@utsouthwestern.edu).

## RESEARCH COMMITTEE CHAIR WINS AWARD

The White House Office of Science and Technology Policy chose Albert Lo, MD, chair of the VA-SIG Research Committee and director of the MS Program at VA Connecticut HCS/West Haven, to receive one of its Presidential Early Career Award for Scientists and Engineers. The award was presented to Dr. Lo at a White House Reception in Washington, DC, September 9.

The award was established by President Bill Clinton in 1996 to recognize and nurture scientists who show exceptional potential for leadership on the frontiers of scientific knowledge. Dr. Lo is also a recipient of Research Career Development Award from the VA Office of Rehabilitation Research and Development.

The VA-SIG is indeed fortunate to have Dr. Lo as chair of its research committee.

## DATES TO REMEMBER

### **January 1, 2005—Application Deadline for Multiple Sclerosis Specialist Certification Examination**

For more information contact CMSC at [www.ms-care.org](http://www.ms-care.org) or Professional Testing Corporation at [www.ptcny.com](http://www.ptcny.com).

### **January 14, 2005—Deadline for submission of abstracts for the CMSC annual meeting**

For more information, contact CMSC at [www.ms-care.org](http://www.ms-care.org).

### **February 12–26, 2005—Examination dates, MS Specialist Certification Examination**

### **April 6, 2005—Early Diagnosis and Early Treatment of MS—What Nurses Need to Know**

6th National Professional Education Program, offered by the National MS Society.

Fresno, California

Contact [robin.rose@can.nmss.org](mailto:robin.rose@can.nmss.org) or [amy.greenwood@can.nmss.org](mailto:amy.greenwood@can.nmss.org).

### **June 1–5, 2005—Annual CMSC conference**

Orlando

Information: [www.ms-care.org](http://www.ms-care.org)

### **September 6–8, 2005—Annual Meetings of American Paraplegia Society, the American Association of Spinal Cord Injury Nurses, Social Workers, Psychologists**

Las Vegas